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Biography

Dr. Neil Schechter is the Director of the Chronic Pain Program at Boston Children's Hospital, an Associate Professor of Anesthesiology at Harvard Medical School, and the founder, President, and CEO of ChildKind, a nonprofit advocating the prevention of all bio-psycho-social pain in children.

Dr. Schechter graduated from Michigan State University, College of Human Medicine Medical School in 1973 and has been active for nearly 50 years in the field of pediatric pain. Dr. Schechter has authored over 120 articles, completed several multimedia appearances, developed several textbooks and book chapters on pediatric pain, and serves as an editor on international and domestic committees such as the World Health Organization Expert Committee on Pediatric Pain and Palliative Care and the Task Force on Chronic Pain in Children of the American Pain Society.

Dr. Schechter's research focus is now pain of children during common medical practice such as injection pain and functional pain.

Interview Abstract

Dr. Neil Schechter begins this interview by describing the state of the pediatric pain field during the late 1970s. As he was training, he "felt it was a bit wrong" to have the disciplines dealing with physical and emotional/mental well-being so divorced from one another, especially with unaddressed psychosocial care for pediatric patients and families during complex chronic conditions such as cancer and sickle cell. Dr. Schechter also recalls a prevalent fear in the medical community of addicting children to pain medication, which kept clinicians from treating children's pain at all.

Dr. Schechter questioned why pain was so chronically undertreated in pediatric patients and participated in numerous academic research inquiries into how to safely prevent pain. With a small community of like minds that he fostered, Dr. Schechter ventured forth into broadly exploring and reframing the way pain was thought of by clinicians.

After Dr. Schechter began to develop a pediatric pain program at the University of Connecticut, he found that pain was often thought of as a psychological construct that was divorced from any biological implications. He worried that this commonly held theory was prolonging harm and suffering experienced by pediatric patients, while also weighing heavily on the clinicians that were referred to work with the suffering children. In several of his works, Dr. Schechter investigated common medical practices and concluded that many of them were causing unnecessary biological and psychosocial harm to children. He also challenged his clinician peers to think about why they would do something to children that they would not do to adults getting the same treatments.

Dr. Schechter discuss how his work built on the foundational work of his colleagues and peers. He recalls several instances he was able to rally similar minds to collectively publish research texts informing and advocating for medical practices to change.

In his local institutions, Dr. Schechter was successful in advocating for institutional reform to improve care that was committed to causing no further biological or

psychosocial harm to kids. This also spurred him to found the nonprofit ChildKind that is committed to aiding institutions in preventing pain for pediatric patients.

Dr. Schechter then goes on to describe the various challenges he faced in his career including peer clinician resistance, divisive national sensationalism of his work, and medical models that were incomplete or lacking in understanding of holistic human well-being. He also explains that some of the bad habits of the past are continuing into the present day practice.

He concludes the interview by describing practices that could be altered to achieve a better understanding of patient health, such as reexamining why hospitals don't prevent needlestick pain when it is within their ability to do so. Dr. Schechter also celebrates the positive advances that have been made for pediatric pain.

Glossary of Acronyms

<i>Abbreviation</i>	<i>Definition</i>
AIR	Assessment, intervention, reassessment
BMJ	British Medical Journal
CBT	Cognitive behavioral therapy
CEO	Chief Executive Officer
COG	Children's Oncology Group
ED	Emergency Department
DPT	Demerol, Phenergan, Thorazine
GI	Gastroenterology
HCAHPS	Hospital Consumer Assessment of Healthcare Providers and Systems
IM	Intermuscular
IBD	Inflammatory bowel disease
IOM	Institute of Medicine
ISPP	International Symposium of Pediatric Pain
IV	Intravenous
JCAHO	Joint Commission on Accreditation of Healthcare Organizations
JIA	Juvenile idiopathic arthritis
MRI	Magnetic resonance imaging
PCA	Patient controlled analgesia
PDA	Patent Ductus Arteriosus ligation
PMR	Physical Medicine and Rehabilitation medicine
UN	United Nations
WHO	World Health Organization

Interview Roadmap



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[00:00:00]

Bryan Sisk: Okay. Today is June 28th, 2019. I am Bryan Sisk and I am in St. Louis, Missouri interviewing Dr. Neil Schechter over the telephone for the Pediatric Palliative Care Oral History Project. Dr. Schechter is in Salisbury, Connecticut. Thank you, Dr. Schechter, for joining me today. To get it started, could you tell me when your mind turned to a pediatric pain as a career focus?

Neil Schechter: Yeah so, I was always interested in the interface of the psychological and physical in pediatrics. Of course it has developmental piece as well; so it was sort of an interesting interface and that was always my interest. At one time I actually considered being a psychologist. And when I went to medical school I considered the possibility of psychiatry, but that just didn't resonant with me because it didn't emphasize, when I went at least, the biological side as much. It was much more strictly mind separated from body in a way that was, I think, unreasonable at that particular time, we now know to be felicitous.

Anyway, so I did pediatrics and after I finished pediatrics I was still a bit unsure of what I wanted to do. I spent sort of a gap year at the Indian Health Service out in the Dakotas and returned as a chief resident at the University of Connecticut. The chief there was a lovely man who took a real interest in my career and really was fundamental and helping me shape my thinking about things. He suggested a fellowship that had crossed his desk that might suit my particular interest and desires. That was in what was then called psychosomatic pediatrics.

It was at Boston Children's Hospital at that time. It had only been going a short period of time and it was basically focused on individuals—children who had psychological problems that amplified their physical problems or vice versa. So, in other words somebody with—excuse me just one second, I have my alarm set here. Somebody for example with diabetes who, for a variety of psychological reasons, would be unable to care for themselves or those sorts of issues and we run this unit.

I was a pediatric fellow, there was a psychiatric fellow, and then there was a head nurse. We had a number of interesting attendings who attended on this unit. Some of the kids, who just stumbled through at that time through this unit, where they would stay for prolonged periods of time, were kids with pain problems that were ascribed to psychological origins. Even though the psychological origins at that particular time were really not necessarily evident, they were assumed because the hardware that was examined in that

era didn't reveal any underlying disease process, yet they were suffering and incapacitated.

So they were put in this unit in and spoke to psychologists for long periods of time. The medical piece was really de-emphasized. Simultaneously with that I was offered a fellow—and that sort of whet my appetite because something felt a bit wrong to me with that. This was like in the late '70s, maybe '77, '78. Around that time, I was offered another fellowship there in developmental pediatrics which really was a fusion of the biopsychosocial model in a way that almost nothing else in pediatrics was true legitimate—looking at temperament individual differences, the biology of differences, biological vulnerabilities of adverse events. A couple with sort of psychological.

It fused a lot of the things that I was interested in at that particular time. Part of that program focused on learning problems and other things, but there was an interesting abdominal discomfort, abdominal pain, with a specific sort of model at that time. And that model was a fair amount more biologically based. But anyway, I had some interest in that and the clinic I participated in as a fellow didn't think much of it.

I was then hired to begin the development of pediatrics program at the University of Connecticut and a couple of things happened. Number one, there was—because the academic psychiatrists were not particularly helpful with a lot of the conditions that they were facing, especially around kids with medical problems, a lot of them ended up on my doorstep. I wasn't particularly prepared to deal with them either, but the psychiatric piece, the simplistic uni-dimensional piece really wasn't helping a lot of kids with cancer, kids with sickle cell in particular, and a number of other problems.

About that time, I had to cover the wards as well, and there were a number of kids we had with sickle cell disease. That became a real interest of mine because I wasn't sure what to do with these kids. They were really complaining continuously of discomfort. The specter of addiction hung over them continuously. It was introduced by everyone from the nurses, and anytime they would ask for more medication there was an eye roll.

Anyway, just about that time, I started to review the literature on sickle cell pain and there was an article and I remember it very clear to this day because it was seminal for me by people called Marx and Sacker. I think they were at Einstein or something at that time. And the article took 38 consecutive sickle cell patients who

were complaining of pain and thought to be addicted and suggested that they were grossly undertreated. And this is in adult literature this was not pediatric literature. And when they were treated more and claimed they had what they would call in this article, or at least came to be known as pseudo addiction, maybe given 5 mg of Oxycodone and or whatever. And then in four hours, undertreated, would wait for that four-hour interval to be up, buzz in immediately in that period, which was immediately assumed to be, of course by the medical staff, indicative of addiction or it's an obsession with the medication.

Anyway, Marx and Sacker said something quite the opposite. So that really intrigued me and I started to look at that time—my eyes were opened with that little, it's almost like a can opener. I don't know the metaphor you would use to explain it, but suddenly I started to look at almost everything that we were doing at that particular time and recognized how little attention we were paying to the comfort aspects of things, to the symptoms that people had. We were just working with the basic assumption that once we cure the disease, if we can cure the pain, the symptom would go away. And that obviously was not the case with sickle cell disease and it certainly wasn't the case with a lot of the other conditions that we were grappling with.

So anyway that was one stream and from that stream we got interested in a number of different things. Just trying to figure out ways that we could ameliorate that. For example, we were first little group, and this was just in a little small university hospital—it was a community hospital part of it—we tried PCA [Patient controlled analgesia] which just emerged for the sickle cell population. But the interesting thing was, there was a revolt by the medical staff there at this particular hospital saying, "You're allowing free access to their veins with an addictive agent to inner city kids who are going to abuse this." There was a very strong—we only wrote a small pilot study about that and I think in the pilot study if you want to look it up, I even mentioned how emotionally tinged this whole thing was and the problems that we had with using PCA for this population given all of the strength of emotion around them. But simultaneously with that, I started to recognize the real limitations of this literature and that same of the pediatric literature on pain just in general.

And so, the first thing I did was, it turned out that my chief of pediatrics was the guy who did the, I don't even know if it still exists but *Current Problems in Pediatrics*. I don't even know whether that still exists anymore, but it was sort of a monograph

that came out monthly on a particular problem, maybe 80 pages or something like that typically. And he said, "You know what? Why don't you write one on pain." And I think that was like in 1984, or '85. And as I started to write this and collect information, it was stunning how little we knew. Stunning. And when I wrote it and it was published, suddenly there was a small community of people who contacted me, who felt similarly. There were people from all over. There was a Canadian contingent, mostly psychologists. There was a nurse whose information I came to value very highly and enjoyed. Even did she come up in your—

[00:10:35]

Bryan Sisk:

Yes, her initial paper that was in that book.

Neil Schechter:

She wrote that book exactly. I actually wrote an obituary on her when she died a little while ago. But so she wrote—you're exactly right Bryan. She wrote this really not very—did this not very sophisticated study, but taking 25 kids on the wards at the University of Iowa hospitals who were all post-op and looked at the type of post-operative care that they received in terms of pain management in particular and it was shocking; 25 kids something like 24 doses of anesthetics through their hospital stay, half of which were opioid. So 25 kids, 12 doses of opioids in total.

Kids who had 20% body burns, fractured femurs, palate repair, a whole host of conditions that one would have thought nowadays would receive a lot more attention. Anyway it was a pretty unsophisticated study and so with the combination this increasing interest that I had looking at that literature, we decided to start to look at this in a more scientific way. So in the mid-80s we published this paper on the status of pediatric pain control of analgesia usage. We took four hospitals in Connecticut. Some were—I had a medical student or research assistant, and we called the charts and looked at four identical problems; 20% body burns, fractured femurs, there were four conditions.

Some in the hospital for more, some from less time. And what was shocking was that no matter what hospital setting, one rural, one academic, the adults received four times the amount—we compared with adults for similar problems—four times the amounts of doses per day that kids got for the same exact problems. And when the kids did get anything, it was IM [intramuscular] and was all predominantly Demerol. That was sort of way of thinking in that period. So, then we decided to investigate why that was so. So we published a paper a few years after that where we surveyed family practitioners, pediatricians, surgeons, I think those were the groups. I think.

And I might be off the track I can't exactly remember. But anyway, what came out of that paper was really intriguing to me, which was the fact—we asked people, "When do you think kids feel pain? What do you think about this procedure, that procedure, how painful it is?" And what striking was that everybody thought that what other people did caused pain and when they thought didn't cause pain. For example, the surgeons were concerned about the bone marrows that we were doing at that time or the lumbar punctures or other kinds of procedures—rating that as higher pain than some of the surgical post-operative surgical pain. The pediatricians obviously thought the opposite. They felt what the surgeons did, and everybody thought circumcisions were uncomfortable because they were at that period done primarily by obstetricians.

So everybody was blaming everybody else but that was in the back of their minds the recognition that clearly there was some discomfort. Although almost 25% of the samples didn't feel the kids under the age of two felt much pain. So anyway, all of these things then led to sort of a low hanging fruit that was out there about ways to start to think about this in a more critical way. So that was some of the PCA work we did.

I think that was very interesting because I was working with at that time a pediatric oncologist named Steve Weisman who got so interested in pain after we started working together that he went back and started doing anesthesia. But we together did a couple of papers looking at a cancer pain in particular.

One of the things we started to do initially was just to survey cancer centers around United States to find out what they were doing for sedation, just in general. And there were 33 different regimens largely chloral hydrate, which is you know is not analgesic. And this has been in this era. This is for bone marrows. The primary one, I don't know if you've even heard this, this is all going to be so archaic, but was something called DPT [Demerol, Phenergan, Thorazine], did you ever even hear that?

[00:15:26]

Bryan Sisk:

No.

Neil Schechter:

That was something developed in the '50s by the French to induce what they call "suspended animation." It was a combination of two phenothiazines. Let's see, what was it? I can't even remember what was in it anymore—Demerol and Morphine, something like that. I can't remember even what the combination was that they developed. But anyway that is what was used typically when

anything was used. It's about 12% incidence of significant side effects with it. It's terrible, but when people were doing anything other than chloral hydrate, that's what they were doing. So, then we said about one of things—the direction we went in was—I'm talking more than perhaps I should. Maybe I should let you.

[00:16:09]

Bryan Sisk:

No, please go on. This is wonderful.

Neil Schechter:

Okay great. So anyway, we then decided to take it in different sorts of directions because there was just such low hanging fruit there, almost everything—no one was thinking about any of these sorts of issues. So from the research side we started to investigate looking for different types of clamps for circumcisions. We looked at different types of approaches for injection pain. And in particular I read this little blip like *USA Today* or something on a plane about Fentanyl lollipops that were being developed by this guy Ted Stanley and they were developed for preoperative sedation, is what they were developed for, but in my mind, I thought, "God, those would be great for kids for sedation like in the ED [Emergency Department] where we would not have to start a line, or we could sedate the kids." And so we convinced them to develop a version of this for kids and we studied it prior to bone marrow aspirations and bone marrow biopsies. The problem with this a lot of vomiting associated with it downstream, but when we did, we thought it was a great idea and it was helpful.

One of the studies that we did that came out of that, which sort of was one of the more interesting things that we did I think and is still quoted pretty frequently, was a study where we got each kid who was enrolled on the study—at that time we were doing nothing but localized anesthetics for the most part¹. And so, this kid who's enrolled into this study was given either a Fentanyl lollipop or a placebo lollipop. And obviously the placebo lollipop kids have more pain than a Fentanyl lollipop. All the kids these kids had leukemia and they all required multiple bone marrows downstream. So for all subsequent bone marrows we gave them active drug whether they were in the placebo group or the control group. Yet the group that had initially negative experience, the placebo group, graded their pain as higher even though they had active drug after four bone marrows downstream, which told us obviously the critical importance of aggressive sedation earlier on in this process and the importance of expectation and doing adequate job in the beginning, so that we don't develop this failure

¹ Weisman, S., Bernstein, B., Schechter, N. (1998). Consequences of Inadequate Analgesia During Painful Procedures in Children. *Arch Pediatr Adolesc Med*, 152(2):147-149.

of sedation so the kids don't develop sort of ongoing anxiety around this.

Anyway, those are some of the papers that emerged during that period. It was at that period as well that we first International Pediatric Symposium. It is called International Symposium Pediatrics—let's see International, I-S-P-P—International Symposium on Pediatric Pain. The first one was held in 1988 and there were about 60 of us there and from around the world really. It was in Seattle. That was a gathering—I met a couple of other folks there and we decided to write the first textbook in this field. So we wrote the *Pain in Infant Children and Adolescents*². We decided to do it on a boat in Seattle Harbor and five years later we had the first edition out in '93 and we had a second edition later. And that's where a cluster of—some of the people who are still active in the field now, Chuck Berde, a number of us we're still together, Elliot Krane out in Stanford—a number of other folks were there at that sort of first.

That also put in my mind increasingly we were working with Steven Weisman and the head of the oncology at our program who was interested—he was a lovely man and he was interested in doing something more for pain for kids with cancer and listened to our lollipop work or this was actually prior to it. So a family who lost a child to leukemia I think it was, gave him a little bit of money and so we organized sort of this conference consensus meeting on cancer pain that we held in Chester, Connecticut. And I think we published a supplement to pediatrics on that, five different aspects of it; Sedation or procedure related pain, disease related pain, and a number of other aspects of that. Steve and I were editors of that, and then there were five sections on that. But again we started to set the mark for that. Around simultaneously with all that a couple of years later, staying in your arena or the one that you're interested in, Kathy Foley—and I'm not sure if you know who that is. Do you know who that is?

[00:21:09]

Bryan Sisk:

Mm hm.

Neil Schechter:

Yeah so Kathy Foley, who was an incredible person at Memorial Sloan Kettering, and actually she was one of the people who added to my interest in cancer pain because they had what was called an observership at Memorial and you could spend a couple of weeks there just looking at what they were doing. They didn't have any pediatric work there but it gave me the mindset to go back and do

² Schechter, N. et al. (1993). *Pain in Infants, Children, and Adolescents*. LWW

what they were doing for adults, for kids at our little hospital. But anyway Kathy Foley was contacted, I think with the WHO [World Health Organization] liaison a woman named Lucia Benini who was an amazing person, is an amazing person still; lost a daughter to cancer at the age of 13 and decided to devote her life to symptom relief.

And so, she funded the first major WHO pediatric cancer pain meeting that was in Gargonza, which is a little walled Italian village where her daughter used to spend summers. And so she brought 20 of us there. And we divided up into groups and came up with some guidelines based on very little information available to us but based on best practices, because by that time there was a fair amount of more sophisticated practice. Anyway that emerged from there. There was quite controversy with that particular time, but anyway that happened as well.

But that could happen and a lot of this could happen because of the development of some assessment techniques to gauge pain in kids, because obviously older kids could tell you something about their discomfort, but kids three to eight had the ability to sequence things, to seriate things, put them in an order, but really didn't have the—they were more concrete and couldn't sometimes give numbers. So there was a whole development that we still use, cartoon versions of that, color versions of that, facial expression. A whole host of other things that we use for that group.

And then there was a development for instance of all these behavioral measures that emerged; a lot of them develop by nurses. A lot of them Canadian nurses who did a lot of this work. Anyway, so we had some more techniques to start to measure some of those stuff so we could do some this research and look at what made a difference. Gradually they got to be a larger and larger group. By '94 this small little group that was 60 people or something, in 1988 was about 300 or 400 in Philadelphia and then it grew and grew and grew. In the last meeting actually, I just got back from which was in Switzerland, and I was there when you contacted me and it's the 12th annual and there were 800 people there. So the field has really expanded very significantly over time.

The only other thing I will just mention around these lines again to stay with palliative care mode was that, maybe it was—I know exactly when it was, it was 2001 because we were in Washington D. C. when the planes hit at this Institute of Medicine committee called "When Children Die." And that was sort of a developing an IOM [Institute of Medicine] consensus meeting basically and we

published a book on palliative care for kids. Marcia Levetown was on that group and that's where I got to meet her. Again, I was the pain person and not the palliative care person, but I was able to contribute to that.

And just to continue with my own career arc a little bit more and then we can start to get into whatever else you want to get into. So, as we started, as more and more anesthesia people and as we developed more assessment techniques and more sophisticated pharmacodynamics, folks got in there and we started to be able to know how to use these drugs more effectively and what their impact was. It felt to me, who was not a scientist in that sort of way, that I could move on to other kinds of things so that's where I got more interested in primary care related pain problems, injection pain, and a number of other kinds of pain problems; in particular chronic pain. And that's where I spent the last 10 or 15 years really as focusing in chronic pain in particular, those sort of pain problems which are very incapacitating.

There's no obvious hardware, let's continue with that metaphor, hardware anomaly, yet the suffering was just as real. They're often disbelieved as not, it requires a trusting relationship. Many of the kids we've seen have been seen by many, many people already who'd been either over investigated and sent off to a psychologist or sent to a psychologist more immediately or more recently—we wrote an article coming out of *Pediatrics*—more recently then given diagnosis that are expansion of traditional diagnosis that used to be quite rare. In particular I'm talking about—I don't know whether you encountered this, but it was Danlos syndrome, mast cell activation disorder, mitochondrial disorder, a bunch of things that have specific definitions. Lyme disease—people have expanded dramatically those definitions because they're a part of their symptom profile; vague sort of symptoms that are similar to some of the problem set that we're dealing with this population. So anyway, so one line of investigation, and I've been interested in that. We're looking at quantitative sensory testing to see whether the nociception is different in that population.

But the other whole arc of my career has been taking what we know and figuring out how to apply it more directly because we know a lot. We didn't in the 80s and early-90s and mid-90s, but by the late-90s we knew a fair amount and we knew enough so that most of it, I mean with rare exception obviously there are some kids with cancer or some problems that we really struggle with, but for the most part if we would apply what we know in a uniform

manner, we can assess and treat the majority of pain problems that we encounter. But we don't for a bunch of reasons.

I became interested in that knowledge translation piece and in particular focused in on institutional commitment to pain management. Not at a pain service level but throughout the entire institution so that everybody is aware the pain is an institutional priority, through signage, through a whole host of other ways through CEO [Chief Executive Officer] support, through mission statements, things like that.

And so we started something like that at one of the academic hospitals I worked at called St. Francis, where we developed something we called "The Ouchless Place," which was a pledge to families that we would pay attention to pain as a part of the child's admission. And when I moved from there to Connecticut Children's and brought that same concept, they made the same level of commitment. There we called it "The Comfort Central," and there were signs in elevator, new hires were told this, there was education, it was ongoing. A whole host of things that we felt were critical and again I published two papers on this if you're interested.

And then we took it to the next level. In about 2006 or '08, we talked to the special interest group on pediatric pain, which you know is basically that ISPP group that I told you about, and got their permission to develop a non-profit which would recognize institutions that did a particularly good job in this arena and give them a sort of a logo and a seal of approval if they met criteria, and there were six, five principles that were felt to be critical.

We were fortunate enough to get some Rockefeller Foundation support and we went to Bellagio, Italy and brought in people from around the world from 13 different countries—20 of us or so to develop these criteria. And so over the past ten years we've really been grappling with this, but we developed something which is called ChildKind. It's actually ChildKind International and we're revamping our website. Now there's about 10 or 12 hospitals that are ChildKind Hospitals. Around the states there's about 10 or 12 in the pipeline. There's a couple that are pending internationally. And simultaneously with that, all of the hospitals had to contribute their protocols and educational initiatives or whatever to a website that would be available to everybody so that institutions that didn't have the expertise on board could benefit from the templates that were created by institutions with more expertise.

And that's where I spend a chunk of my time these days doing that. There's a couple of—I just wrote one paper on it in *Pediatric Pain Letter* that describes the whole ChildKind thing but there's two other papers that I wrote about that whole concept of institutional commitment to pain. So that's a big blather on my part but that gives you a little bit of the arc. It started out with the recognition that this was an issue. Then one stream of information, the gathering of information through the initial monograph. Then I did pediatric clinics in North America and that led to this textbook. So that was the one whole piece of information.

Also, I have been on a zillion committees, again, that were consensus committees consolidating information that we had. The WHO committee on cancer pain, the American Pain Society meetings on chronic pain, the Cochrane Group, we have a Lancet commission on pediatric pain, there's our consensus meeting on needle pain—so, one thing after another. So that's been that whole sort of information gathering, consensus building, advocacy piece. And on the other side there's been the investigation piece which looked at the initial differences, some of the attitudes that foster those differences in prescribing. And then little projects here and there that attempted to at least chip away at issues to make things a little bit better for kids who are encountering medical care. So that's kind of the story, I guess.

[00:32:55]

Bryan Sisk:

What a story. Wow. I have a bunch of branch off questions. Starting it back at the beginning and working our way up. One thing I've been really wondering is about a lot of this history what the on-the-ground reality was. And so first I want to think about that U.N. [United Nations] article that came out. My understanding was that was a chapter in a fairly obscure nursing textbook.

Neil Schechter:

Yeah, I'm thinking about it. I'm not sure how true it was, but yes that is what it was, it was a chapter in a nursing textbook quoting her master's thesis which I got a copy of from the University of Iowa Library. That's exactly what it was.

[00:33:37]

Bryan Sisk:

So how much of an impact did that have initially?

Neil Schechter:

So that had huge impact. Huge impact. Again, not in the medical community per se. In the nursing community however, it became very well-known. And in that particular time there were a number of nurses, Margo McCaffery was one from the adult side. There were a number of nurses who were leading the charge. Again, because when you close the door and the doctor goes off to chart and whatever else they have to do, the nurse is sitting there.

So, it turned out to be a lot of the assessment stuff all the pediatric assessment stuff Judy Beyer was in Colorado. She did the Oucher, Celeste Johnson and Bonnie Stevenson developed all the preterm and infant pain stuff, the infant thesis stuff. Donna Wong developed the sort of Faces scale. All that came out of nursing, so I think it had a dramatic impact on nurses per se.

I'm not sure honestly, it's too far back for me to remember how I came up with it but I have a feeling and there wasn't such a thing probably as PubMed at that time, but somehow I must have seen it referenced in something that I was looking at and then went back and looked at it. But then she became famous for the sort of myths and misconceptions that she felt that promoted that undertreatment. The main one was that the kids didn't feel pain, that their nervous systems were underdeveloped and really, they didn't experience pain. But that was the main one that she implied and obviously neuroanatomically there are differences in a developing nervous system but that has nothing to do with it though.

We know that at multiple levels now in a much more sophisticated ways with fMRIs [Magnetic resonance imaging] and everything else. But we obviously knew it just sitting in the room; didn't take a genius to know that somebody was suffering. So that was very impactful for some of us and those myths are still quoted even to this day I would say when people do this. But again, how that got from that, as you mentioned, from that textbook to being the coin of the realm for those of us who were interested, I don't know.

There was another thing that spread similarly which was unfortunately problematic. But again, these things, people were looking for things that would support their observation. So the other thing which was really important, and that was, what's his name? Somebody Jick. I forgot the two names. Anyway, it was a letter to the editor of the New England Journal in the '80s, and it was from two people who ran what they called the Boston Drug Surveillance Project. This was a letter to the editor³. It wasn't an article and they reported on 11,000 adults. These were all adults. This whole literature is adult. Who received Demerol post-op and four of them became addicts, stating that they didn't think there was a genuine risk of addiction in people who used these medications for legitimate purposes. And that became part of our conventional wisdom I would say; had a life of its own and was part of the belief system of most of us because we were convinced that, that was so.

³ Porter, J. & Jick, H. *Addiction Rare in Patients Treated with Narcotics*. [Letter to the editor]. New England Journal of Medicine, Vol 302(2), 123.

But anyway, yeah so that's how the Eland thing got about. The intriguing thing is that Jo would lecture but she was a nurse. And when she would do ground rounds, as you could imagine especially in that era, there was limited respect given for her opinion. And again, she was talking to groups largely of surgeons who had a practice pattern that totally denigrated pain. And it was hard for somebody who's been doing something for 25 years and causing significant discomfort, but you've had enough cognitive dissonance to think that, "You're not really doing that. It's not really causing that much pain. You're doing an adequate job."

For somebody to put that in your face, especially if it's a nurse, was really unacceptable. So we on rounds together and literally she would be attacked by these people and I have to stand up there. At some of these I remember very specifically at one upstate New York hospital where there was an angry surgeon responding to this. And again, because I'm not an acute care person my credibility wasn't that much better. I would say I was in between a nurse and a surgeon and but even so I was a lot better than her. But that is how it was. The field was very non-responsive, especially in the newborn world. In the newborn world it was bad enough for post-op, but in newborns, we were obviously doing circumcisions but above and beyond that, we were putting test tubes in babies without any sedation. We hardly had any local anesthetics typically doing LPs [lumbar punctures]. The markers were thought to be blurred if we put in local—so there were all kinds of things that we were doing that was real, real cognitive dissonance in that period. And that probably until Sunny Anand's work—are you familiar with that?

[00:39:13]

Bryan Sisk:

Mm-hm.

Neil Schechter:

Okay. Until his word came out and codified the massive outpouring of toxic hormones if you will, that occurred when somebody did a PDA [Patent Ductus Arteriosus] ligation with and without anesthesia. Suddenly as soon as that work came out, seven journals came out with editorials saying it was barbaric to do it any other way. So you know little by little that was disruptive technology or whatever you call that these days. So, that was Eland's thing and I don't know how it spread. I got to know her very, very well. She came to this house out in Berkshires actually. She was a marvelous person. And then she took it at the next level. She trained her nurses, she developed work-ships, they went to Italy, and she developed with Lucia Benini who funded some of her padres of nurses who trained other nurses there in Italy.

She then did the same thing in India. So she just spread the word at the nursing level and a lot of the nurses were taught to demand accountability for this and that's been one of the issues. Who's accountable for this pain? And if you can't do it, who's the next step up in the chain to demand that to make it go through their own chain of command? And so she emphasized the humiliation of people who were not doing adequate job with this, "If you don't know enough to do this, then look at this paper. If you don't enough, who's your attending?" Yeah so anyway that's the Eland story. She became a hero really and developed the American side of pain management nursing and a bunch of other kinds of things.

[00:41:03]

Bryan Sisk:

So, we talked about how some of these cognitive dissonance and some of these just lack of awareness or appreciation of the pain that mainly physicians were inflicting was one of the barriers to effective pain management. Were there any other barriers?

Neil Schechter:

[00:41:26]

Bryan Sisk:

Well, I'll tell you a story. Again, we have time, right?

Neil Schechter:

Okay great. So, the paper we published in '86 on status of analgesics usage in children⁴, the one that I mentioned initially. That was my first major paper I published paper in clinical reports or something like that. I was in an institution at that time. Now I'm at a fancy place and they have a very strong public relations department, public information department that would protect me basically. In other words, they would send people with me so I wouldn't be misinterpreted, all that kind of stuff. But at that particular time, I was at the University of Connecticut and there was no such thing really. And so, I published this paper and the way it was interpreted, even though if you re-read it sometime in your leisure if you choose to, I was very conscious and not trying not to be a self-righteous prick and the accuse everybody of doing a bad job and saying "you're doing a terrible job." I was merely pointing out, there were differences between adults and kids, and we can do a better job. But the media loved it. They loved it and they thought that I was the canary in the coal mine calling out something, that's probably not the right metaphor because we were all not dying, but that a hero was—

[00:43:06]

Bryan Sisk:

The whistle blower almost.

⁴ Schechter, N., Allen, D., Hanson, K. (1986). Status of pediatric pain control: a comparison of hospital analgesic usage in children and adults. *Pediatrics*, Vol 77(1), 11-15.

Neil Schechter: The whistle blower. The Puritan standing with the light and exposing all these horrible doctors who were doing all these terrible kinds of stuff. So they loved that. Suddenly I get home from work that day, and I was exhausted and it had been published that day, and my wife says, "Where the hell are you? You've gotten 40 phone calls about this." And some guy from the AP [Associated Press] calls, I call back and he says, "I haven't had the time to read the 100 word synopsis of this article—can you tell me it?" And what they're trying to do, it felt to me, was to have me oversimplify and give non-nuanced sort of statement about what I was trying to do.

But anyway, regardless of what I tried to do, I felt it was entirely misinterpreted. I was even on *Good Morning America*, one of those shows and in the morning, and the guy was basically—I was trying very hard not to be in anyway inflammatory to suggest that this is—because people are bringing their kids to hospitals. And suddenly they're informed that—you can just imagine if your kid was scheduled for surgery the next day, that's probably 200,000 kids around the country and somebody is saying "more than likely your kid will suffer unnecessarily."

So anyway, this spun out of control. I couldn't stop it and I was scheduled for some other interview and I was constantly trying to, not undo but nuance this. And the guy said, "I'm sorry, we're scheduled to have you, but would it be okay if we postponed this? The challenger missile blew up." I don't know if you remember, but in '86 I was with a teacher who was on the spacecraft and was one of the seven astronauts who died. And so I said, "You know, I'm good with that and I'll flash in the pan. If I flash in the pan again you can call me, but I'm done with this."

So anyway, that was what we were facing at that particular time. There was a lot of blow back. There was a lot of misinformation. There was a lot of resistance. Although surprisingly not as much as I anticipated especially when the data was out there about how to do this in a better way. So for the most part, people relatively quickly latched on to some of these things. There were still subtle things, Nuss procedures, scoliosis, there are still procedures in which we didn't have good protocols in place. But for the most part the typical kind of pain scenario we started doing a better job.

[00:45:56]

Bryan Sisk: How much did fear of not knowing how to dose this or fear of harming the children with the medications, how much do you think that figured into this hesitance.

Neil Schechter: I think a fair amount. I think a fair amount in the beginning. We really didn't know the dosing, so we tended to use what was then called weak narcotics; codeine in particular was used and you know the deal on codeine right now—the lack of an enzyme that 10-40% of people have. And so, they were given acetaminophen with codeine in it and they ended up with basically just acetaminophen. Or it was rapidly metabolized and they ended up having side effects in about 10-12% of people. But that is what we were going to, if you will, because they thought that was safer.

The other thing was IV [intravenous] medications. In the beginning people were reluctant to use these meds on the full IV so they had to be used IM or orally because they thought these kids needed to be monitored before they used any of the IV opioids. Again, it sounds like an entirely different world as you can imagine. But there was some genuine reluctance to do that out of fearfulness. That turned around relatively quickly, especially when there started to be more consensus statements about it. So, there were some back up, if you will, against the possibility of litigation or other kinds of things happening if the professional societies were endorsing these kinds of things.

But in general, that was the lack of knowing how to do it. But what we ended up doing was IM Demerol and that was the standard of care. And just imagine that it was every four hours and just imagine if you had to call the nurse to say that you were in pain and you knew she was going to come in with a big needle. You would not. It would quickly be a disincentive, if you will, to say you're in discomfort, to say you're in pain.

[00:48:26]

Bryan Sisk: So you talked early on when you were going through your training and fellowships how there was kind of this sharp distinction between psychological issues and pain issues and physical issues. When did those concepts start to blend into a more holistic view of pain, in a more holistic view of patient experience?

Neil Schechter: Well what do you think? What do you see now? I mean I was at a meeting and I was giving a talk on chronic pain. And actually the talk I give is on the origins of the nomenclature for these conditions, functional conditions if you will. I'm not talking about right now, but you actually can have persistent pain in kids with cancer who's under control, right? With kids with sickle cells whose episode is under control. Kids with IBD [Inflammatory bowel disease] whose inflammatory markers are fine, but you still have sort of a hyper sensitive nervous system that is overly responsive. So I would suggest that even to this day, there's still a

lot of a dichotomy between people who say, "Well he doesn't look like he's in pain."

Well, a lot of that still exists to this day. From the pain world, I would say in the past 15 years or so, but the most recent edition of *Stedman's*—which the printed one was in like 2006, that is about what 10, 12 years ago something like that—it says functional disorders and it says something where, "the symptoms without an obvious organic explanation," blah, blah. And then it says, "See neurosis." So as late as that, they were still making that sort of distinction, even though we obviously do not think that is the case at all anymore. That obviously anxiety and depression might amplify a biological vulnerability, but is not the cause of it typically. But the field still dichotomizes this a bit I would say.

Sophisticated folks don't—I know in your training where you go—so sophisticated folks for headaches, for functional abdominal pain, for fibromyalgia, for IBD, they'll still stick. They will have to explain it using of metaphors and a whole host of other things—that your pain, more investigation is not the solution to this but that does not mean that this is an incapacitating pain and that your nerves are like sun burned and hypersensitive. So that's actually some of our recent research in kids. But I would say even to this day there's still that Cartesian sort of dichotomy.

[00:51:13]

Bryan Sisk:

And as your data was coming out, you know the Eland came out, your data followed it in the mid to late-80s.

Neil Schechter:

Correct.

[00:51:21]

Bryan Sisk:

What was the gap between that data coming out and starting to see major changes in actual practice? When was the data able to crack through some of the resistance you were getting from the surgeons and from other physicians?

Neil Schechter:

Yeah I would say stunningly; number one we started to have more assessment stuff, which was great. But stunningly it was Sunny Anand's work in 1987 or '88 that really changed everything. As I mentioned, if you look shortly thereafter there were in the *BMJ* [British Medical Journal, in the *New England Journal*, in *Anesthesia & Analgesia*, every major journal started to say it is barbaric to do what we historically been doing in terms of the lack of adequate treatment of pain and the lack of adequate anesthesia. So that sort of did it.

There was still resistance. People still didn't know how to do it, but there was a mindset change especially in the younger physicians. Now again the younger physicians in their training are very much influenced by senior physicians and so there were still settings where that was so. But chief residents, other folks who were at the top of their heap, if you will, started to incorporate these things and it really took time. And again, I don't know other settings. I mostly know my own setting.

But even to this day, if you do a blitz in hospitals, folks at Sick Kids for example did a blitz a few years ago, and they felt that about 20% of kids were inadequately treated. And that's been the standard number, about 20% even in sophisticated hospitals. And as you could imagine, in low and middle resource countries, it's 80%, 90%, 100% of people don't have adequate pain management especially around palliative care.

When you talk about palliative care, I'm sure some of the people you'll interview will be good at that, but that's completely unbelievable in some of those countries where they don't even have access to morphine. But in sophisticated hospitals it typically runs, if you look at that literature, about 20% even now. You can't really be perfect but then things are much better

For example, we did a study at Boston Children's extracting data from the electronic medical record over two years and we had a million pain ratings. Of those, we tried to look at those over 7 for over a day or two, and that was less than a percent. And they fell in very predictable patterns. Some were orthopedic kids, some of the kids with what used to be called conversion or functional disorders acute and chronic whatever you call it, and sickle cell kids. Those were sort of the three arenas, and we developed sort of interventions to address as best we can in all those arenas. But anyway, so I think we're doing much better but there's still probably still a ways to go and I would venture a guess. What hospital are you in? Where are you now?

[00:54:44]

Bryan Sisk:

Saint Louis Children's at WashU.

Neil Schechter:

Yes, so I would venture a guess that even at your place, if we did a blitz there would be people who were not satisfied with their post-operative care. By the way, one of the leading guys on the palliative care group that I remember was a guy named Sesh Coles is he still there?

[00:55:06]

Bryan Sisk:

He's just retiring this year.

Neil Schechter: So, he's a neonatologist and he represented that whole arena now that I think about him. Anyway, so I would say that that was changing, the recognition became increased gradually or pretty dramatically the practice changed gradually.

[00:55:37]

Bryan Sisk: Well take a step back thinking about palliative care and pain, they were kind of developing with similar content area at about the same time in pediatrics. What was the interaction when this starting out in the late 80s early 90s? Was there a lot of cross talk between the people that were pushing pediatric palliative care and people that were developing pediatric pain as a specialty?

Neil Schechter: You're right on target. That's a great question. There was not. There was hardly any cross talk which is sort of shocking, right, depending on the institution. It was sort of shocking. Considering in some institutions now they are in the same divisions, if you will. But there wasn't a hell of a lot because a lot of the pediatric palliative care work came out of oncology and so a lot of people would come out of the oncology groups. What is that group now called, COG? I don't know what that group is called now.

[00:56:37]

Bryan Sisk: Yeah COG, the Children's Oncology Group.

Neil Schechter: Yeah so some of the work sort of came out from those kinds of big people working in that. I know that a lot of the early people were oncologists. I don't know if Joanne Wolfe started as an oncologist but a lot of folks did and so it came out of that group. The pain group came a little bit more of anesthesia at least in the beginning, and even though it was sort of nursing, it tended to be less end-of-life care, although a ton of kids were dealing with neurodegenerative diseases in the beginning or whatever. And there were always these kids that would be screaming of unknown origin of stuff that was attributed to pain but nobody could find it and kids would develop mental problems.

But shockingly there was not a ton of crosstalk and there should have been because the philosophies are so similar. So bio-psycho-social involved, being sure that the parents are brought in, the language that's used. But so, for example one of the things that I was really intriguing to me when we did this IOM report, what I always took away from that—we interviewed a number of parents who lost kids and when we asked them, "What would have made a difference for you if anything. What would have made difference?" And the parents who reported basically that they felt that they were the general contractors and they had all these subcontractors, and nobody was a general contractor.

And that would have been the question who's that general contractor? Is it the palliative care team? Is it the oncologist? Who is it? We didn't have a similar coordination of care issues, if you will, for most of our pain kids in the same sort of way. So it was a little different in terms of marshalling of resources. It would be mostly some drug choices, there would be some psych stuff, but it wasn't bringing together the oncologists and interventional radiologist and this that and the other and a GI [Gastroenterology] doc—all those people that are necessary in coordinating the care of some life threatening or life-limiting conditions. So it's a little bit different, but shockingly there was little crosstalk and we could have probably learned a lot from each other and still can, I think. In our place now, there's only one of our pain doctors who's really interested in oncology.

At this point the palliative care folks are pretty good at everything except doing unusual catheter placements for kids with really challenging kinds of problems that are really towards the end-of-life who they put in catheters hoping to make them comfortable or do lysis block or another. But for the most part, most of the medication management is done by palliative care, we don't see many of those kids.

[01:00:01]

Bryan Sisk:

So over time has this persisted as parallel tracks or diverging tracks or has there ever been any additional cross talk between these specialties?

Neil Schechter:

Well, again I can only speak to my own experience, which is limited, just in a few institutions. But for example, in our institution there's comradery, but I would say not the sort of close friendship that probably we would expect. That could be a function of personalities; the person who runs the pain—it could be any number of things in this particular setting. In the previous setting where I was until 2010, there was a palliative care individual oncologist who was working on really hospice related kinds of stuff and we would do some of the pain management for her.

But I would say the symbiosis that should exist between the fields, at least in the settings that I was in, is not as strong as it could be. But I do, for example, I do lecture the palliative care folks. I have a slot each year for the new fellows on pain management, but it's really focused on chronic pain not so much on acute pain because they have that down pretty well.

But that's a very interesting question and I've often thought about like what you're doing, looking at the histories of both of these

fields which were sort of came up in parallel. It was like Neanderthals with Australopithecus, I'm sorry, I forgot what the hell we are. And one them wasn't a dead end like Australopithecus africanus, whatever the hell that was, was a dead end as we evolved. So we evolved sort of together but never really intermarried. But I know in certain places there are pain and palliative like Yukon now there's a pain palliative doc and that's in observational pain and palliative care and I bet that is so at other sorts of places. Where I am, it's not.

[01:02:35]

Bryan Sisk:

So from your perspective as you were forging a career in pediatric pain before pediatric pain existed as a specialty, what were the biggest challenges you faced?

Neil Schechter:

Well, to be perfectly honest, I really didn't feel a lot of resistance. I felt well accepted. I gave grand rounds all over the United States. I felt relatively, with rare exceptions, relatively people heard what I had to say and again in that era I was talking mostly about very general kinds of things. The drugs themselves that people didn't know much about. How to use morphine, how to assess discomfort, that sort of stuff when I was talking about acute pain.

There was some really not a lot of resistance. I was able to frame it. When you frame it from a patient experience point of view and we're not accusatory, most people wanted to do the right thing. And if you gave them that information, they were good with it and that's why we developed all these consensus things and some were put in place and some weren't put in place. But I wouldn't say, obviously some of the surgeons had some resistance.

They were but almost immediately, for example, at Yukon very quickly we were at the children's hospital. The pediatric surgeons were really accepting of this and looking for help. I mean really looking for help and in certain ways they felt closer to pediatricians than they did to surgeons. Even the orthopedic surgeons, they really were looking for help. And when we raised that specter they said, "That is great." And so, I didn't really feel a lot of—

It was an idea whose time had come and so I wouldn't say like Joann Eland who encountered a lot of resistance, in part because she was a nurse, she was a woman, she was telling docs what to do. They didn't hear it and that person was very, very forceful. But I felt done the right way, in an unaccusatory way providing information, we could have significant impact. And that was with rare exception, with rare exception.

And so, having said all of that, there's still 20% of people are still suffering needlessly and we haven't gotten very far with the needle stuff yet. There's still been challenges to that with use of topical anesthetic and stuff like that and who does the, who has to write the order, this, that, the other thing. There are some of the obstacles but for the most part, like in Boston Children's now we got 50 kids a day on the acute pain service. The PCAs and some stuff like that the surgeons are happy to do that. And we're doing regional stuff that was another major advance.

So, I would say looking back at the length and breadth my career, I mean, I was really felt accepted. We identified a gap in care. People were looking for solutions. We could offer some solutions and for the most part were accepting. Now again I worked in a bubble and my chief of pediatrics was at Yukon. I mentioned the other person Mark Richards previously, he was very accepting and very supportive of my career. And then the chief of pediatrics at St. Francis in Yukon was my best friend who was a fellow with me and he was very supportive. So I never really felt a tremendous amount of resistance to that.

Yeah funny when I think about it in that way. But I didn't feel it. And again publishing, it's an interesting thing maybe lesson for your own career, when you identify an arena that's a bit under researched, a thing if you will, this is what Mark would call it, "You have to find a thing. " If you find a thing and publish a little bit on that thing, suddenly before you know it, you're the person who knows about that thing and especially if it's in an area that's not—like what you're doing even now, I mean your history. Suddenly you're known as the person who knows about that thing and so you get invited to talk about it. And so we started with pain awareness.

And then the other thing I didn't mention that was really very, very, very helpful was in about 2001, 2002, it was JCAHO [Joint Commission on Accreditation of Healthcare Organizations]. And at that time, I forgot her name right now but she's another angel in this field, a woman from the University of Wisconsin who's a pharmacologist who was interested in pain. I forgot her name I'm sorry. But anyway she nagged the hell out of JCAHO saying that pain should be a marker, that pain should be included in how you evaluate hospitals. Here is the data on patient experience.

Suddenly in 2001, 2002 people had to look at pain assessment, looking at reassessment as well, doing AIR [Assessment/Intervention/Reassessment] cycles, assessment,

intervention, reassessment. And suddenly with all of that, pain became a thing, and so we were kind of needed by the institutions. They needed somebody to this, to develop protocols with them and change practice. Because otherwise they wouldn't to be approved by JCAHO, and that was a big deal. That was a very big deal and that was almost instant legitimacy.

Now, when you read the WHO publications from the people who were into the opioid epidemic, discussing it that way, are claiming that the pain is a fifth vital sign and all that stuff that people were using, there was sort of ill intent. That definitely was not from my perspective. Having said that, awakening everybody and asking them about their pain after every four hours and having to respond to it—typically, you're not going to respond with cognitive behavior certainly. You're going to respond with an opioid and so that might prime that pump a little bit. But anyway, I think JCAHO is a critical aspect in the history of all this. The importance of a governmental or quasi-governmental agency that holds a hospital's livelihood in their hand and demanding that pain be attended to was very helpful. On the other side of it there was all these reports that hospital gets, you know they solicit these things. What are they called? Some bunch of questionnaires that patients get when they leave?

[01:10:20]

Bryan Sisk:

Oh, the HCAHPS [Hospital Consumer Assessment of Healthcare Providers and Systems].

Neil Schechter:

Yeah, that sort of stuff, a number of those kinds of things. They're asking about their experience and many people are reporting an advocacy of pain management and that then empowers the institution to sort of go ahead and do something and to ask for something to be done about that. Some sort of intervention.

[01:10:39]

Bryan Sisk:

I got a couple of questions left and I'm going to frame the questions related to kids that are suffering from serious illnesses. If you feel like you can answer better for a different population, take it whatever direction you want.

Neil Schechter:

Sure.

[01:10:55]

Bryan Sisk:

Over your career, what do you think has been the biggest changes in the care provided for kids that suffering and even dying from serious illnesses?

Neil Schechter:

Yeah, well again it isn't my area, but I will say the attention to symptom control and to the psychological well-being of those kids

has been dramatically, dramatically changed. Has dramatically changed the kind of work you're doing, which is really God's work really, has really had an impact. And when people can die, and again staying with life-ending or life-limiting conditions, with some sort of dignity at home, comfortable, and again with catheters, with adequate pain control, with adequate psychological support, that has been a dramatic, dramatic impact.

I will say with other kinds of conditions so, for example, I work in an abdominal pain clinic and we would see a lot of kids with IBD who have pretty significant disease. Their disease is under control but they continue to have persistent symptoms. Those kids I would suggest, and I would suggest the same with JIA [Juvenile idiopathic arthritis] and maybe the same with, post brain tumor kids, post resections—those kids who no longer have either increased inflammatory markers or active disease that we can measure by present technology, they often have persistent discomfort. I would say we don't do a great job with those kids. We don't do a great job with those kids because we're still going after what we perceive as the elephant in the room. Even though the elephant has been addressed in a significant way and then you tend to attribute it to psychological causes.

And it's easy to think that a kid with IBD who's going to run to the bathroom every 20 minutes and doesn't want to go to school, and now that's under control, but has gotten so far behind in school, and the stress of catching up and explaining where they've been, and this and the other thing, might be challenging so that they would psychologically, even if they were better or not, not want to go. Not infrequently but there's a hypersensitivity that has emerged in their nerves as well and that piece needs to be addressed.

But I would say in terms of the kids you were talking about primarily, the kids with life-limiting illness, that really from what I saw in the past, horrible vomiting and mucositis that was untreated or we did not know how to treat and other kinds of things. There's been a much, much, much, much improved situation with that. So we do get the rare kid who they're really struggling with, but for the most part either the palliative team or our team can do something so that nobody really, so that most kids don't suffer horribly and we can typically do something. Again, I'm not speaking out of expertise so I'm not the right person to address, but that's my sense and I have my eyes open a bit to that. But that's my sense of in a place like ours, a place like Dana-Farber. I know Joanne and those kinds of people could certainly talk to that more in a more sophisticated way.

[01:14:57]

Bryan Sisk:

And the last question, I would really love for you to dream aloud. Thinking about children in pain in general, how you would want to define it. If budget, politics, resource limitation, stereotypes, bias, if all of these things weren't obstacles, what would you ideally want care for children in pain to look like another ten years?

Neil Schechter:

That's a great question. So I guess I'd see in a couple of different arenas. So, in hospital and this happens for the most part now, but I would say pretty much every procedure, there shouldn't be any procedure that kids are inadequately sedated for. And that includes any sort of skin breaking procedure. So there definitely should be adequate sedation, even for IV starts or even for blood draws or anything like, that there should be topical anesthetic. So kids shouldn't encounter discomfort. And I know it sort of as an outpatient—you're a pediatrician. You're a pediatrician by training so you've gone into the clinic right? And kids at the beginning of your visit cowering, "Am I going to get shot? Am I going to get a shot? Am I going to get a shot?" And that's all because of the sort of preoccupation with needle with skin breaks. So I do think in hospital for sure we can do a better job with—there should be no procedures, zero procedures that cause much discomfort.

I think care needs to be decentralized around pain and that's sort of a ChildKind thing that I'm talking about; that everyone is attentive to when parents are asked, "What's the most important thing about this hospitalization?" They will initially say, "Obviously curing my child of whatever the disease is." But the second one would be, "My child's comfort during the process." And when asked about the level of satisfaction, the greatest disparity between their goal and their satisfaction is in the area of comfort. So, it was 2008 or '09 when that survey was done.

So, I do think decentralization of care where everybody is attentive to it. People who bring the food trays, people who sweep the floors, the nursing service, whatever. Everybody is aware of this that there's accountability in a clear way for who's responsible for keeping kids comfortable. Is it the attending at that level? Is it the pain services or the nursing services? Where is the accountability as somebody is struggling? I would certainly like to see that.

I think one of the problems that we're encountering now and that you're going to encounter in a major way is this revolution with opioids that are going on now, which is very, very, very unfortunate and a gross over simplification of a complex problem. Obviously Purdue was horrible at some of the things that they did,

but this issue is not strictly that we have OxyContin. So it's a far more complicated issue, yet opioids are being painted with a brush and people with legitimate problems are afraid now of even the short term use of opioids let alone people with life-ending illness which is crazy. But we hear of that so I would like it to be a better understanding of that. I would like most pain management to be multidisciplinary. I did mention child life and stuff like that, they're an absolutely critical piece of it. So that every hospital would have adequate child life resources for them to be helping them with anxiety around the hospitalizations itself and especially around procedures.

So inpatient I would see a multidisciplinary approach and really attention to post-operative management to lots more regional anesthesia, which is a big deal and we're starting to use a tremendous amount in our institution. The fact that most procedures or every procedure is treated with something, either it's nitrous or in some places local anesthetics where it's found to be necessary or whatever. But that there's no build up like I mentioned in my earlier study with bone marrows with anticipation of the next procedure amplifying your discomfort.

As an outpatient, I do think again, skin breaking procedures is another issue that as outpatient I feel is important. I think there are other painful things that we routinely do as outpatients and some attention to them might not be a bad idea. But I don't want to create a bunch of kind of wimps—not to say that no one should ever feel any discomfort that's ridiculous. And sometimes we can't alleviate the pain in the hospital or whatever, there's still some. But obviously we can typically do a better job.

There are all kinds of new research. My colleague is developing a long-acting local anesthetic which will last for days, four days at a time. So it can be used in the wound after surgery and you won't really need other than non-steroidal downstream because it will basically eliminate the discomfort in those nerves that have been cut.

But anyway, there will be lots of other kinds of stuff I think coming down the pike. I hope analgesics are not too stymied by the concern of opioids. But I feel a trajectory of what we've done over my lifetime has been dramatic. There was a paper I wrote. I quoted a couple of papers. We were in the 80s, you looked at the number of articles that were published on pediatric pain, it was like five or ten or something, and half of them were mine or somebody.

Very, very few in the pediatric literature *per se*. And now when you look, a lot was in the nursing literature or whatever, but now when you look there's thousands, on pediatric pain thousands. And the scope has been quite dramatic. When we started, somebody named Rana wrote another letter to the editor⁵ maybe to *Pediatrics*, or something like that. And this person looked at the top ten pediatric textbooks. This was in the late-80s I think, early-90s, and found in all of the top pediatric textbooks, there was like ten different textbooks, a total of a page and a half that was devoted to pain and a chunk on that was on sickle cell. So there was nothing in that.

There was no advice of what about what to do. Whatever there was nothing there. And now there are multiple textbooks on pain every chapter. There are pediatric texts lots of people have written them. The major pediatric textbooks have chapters on pain, and you'll see some chapters on development and stuff like that. So, the uptake has been very, very dramatic. I anticipate the continued growth.

One of the issues we are facing, and again this is more inside baseball, but it in the world of pediatric pain you can't be board certified unless you've done an anesthesia fellowship a neurology fellowship or PMR [Physical Medicine and Rehabilitation] fellowship. So a pediatrician couldn't be board certified in pain because it comes out of anesthesia. We're trying to change that, a group of us, so that pediatricians could take a pain fellowship and be boarded in pain subsequently, but that might have a real negative impact. It's having a negative impact and it's hard for us to find pediatricians *per se* with an interest in this arena. So, we're trying to grow some to replace ourselves

But in particular that's sort of an issue. So, manpower is going to be an issue. Another thing I'm writing there's a Lancet commission on pediatric pain that we're just getting started with it writing a section on it on organization of care. And certainly there will be more and more things on telehealth, and internet based care, internet based CBT [Cognitive behavioral therapy] in the future to address chronic and persistent pain problems. I think those are inevitable. I think as I mentioned there will be new medications and again the importance of a multidisciplinary approach—this can't be understated.

[01:24:25]

⁵ Rana SR. (1987). Pain-A subject ignored. [Letter to the editor]. *Pediatrics*, Vol79(2), 309.

Bryan Sisk: I got one other question that came to mind that I would love to ask you.

Neil Schechter: Sure.

[01:24:32]

Bryan Sisk: Thinking again about five years or ten years from now, what do you think would be the ideal interaction and relationship between pediatric pain medicine and pediatric palliative care?

Neil Schechter: Well, I would see—I mean they're so similar in so many ways that I would see if it at all possible, I don't want to diminish one or the other, but one being under joint leadership if at all possible and something independent. Whatever we wanted to call that division, symptom control or whatever. But they would share ground rounds. We don't do that where we are right now which is crazy. They'd share journal clubs, they'd share the rotation for our pain program—and there is for our pain fellows, they have to spend some time in palliative care. Yes, they do, but it would be a much more important part of the rotation.

I don't think the palliative care folks spend any time with us to be perfectly honest. It's not bidirectional at this juncture but I would say spending time during the fellowships with each of us, because there's a lot to learn from each other. We have, for example, once a month I would say, we have joint surgery and anesthesia ground rounds. Why we have not joint pain and palliative care ground rounds, every twice a year or something? It doesn't make any sense. Or more frequently than that. So I would say we have a lot to learn from each.

I don't know about the defensiveness, "You're doing my stuff, I'm doing your stuff," how we tamp that down where it exists. I don't know where totally it exists but I'm guessing. The fact that we don't see a lot of kids with cancer suggests for the most part their pain management is being handled in palliative care, so I don't know. But I would say certainly a closer relationship makes sense.

And as pain medicine is becoming much more anesthesia focused unfortunately. That's our big problem now but it is—a lot of the training is in anesthesia. They can bring something that the palliative care folks don't have but they don't have a lot of else, so they really would benefit from our anesthesia colleagues but from some traditional training through palliative care.

But anyway that's where I worry the fields might be moving a part in terms of the personnel because anesthesia, they don't like to live in ambiguity. They like to tuck things in at the end of the day. A

clear beginning and an end. They like to help and know that they're helping. And with pain and with palliative care, that isn't usually so, especially chronic pain and palliative care in general, these problems are ambiguous at times, they're draining, they're emotionally draining. Sometimes the families have a hard time being grateful or appreciative. They're sometimes angry given the lot that they felt they'd been dealt, the cards they've been dealt. So I do think the temperament of personality of people going into pain is quite different than the people going to palliative care. So, I'm not sure what that's going to do to the relationship honestly.

And I don't know what funds are going to drive them either at the other kind of thing where depending on coding and an additional support. I don't know what that's going to make things more or less procedure driven or more or less viable. It's interesting times.

[01:28:48]

Bryan Sisk:

Absolutely, this has been phenomenal. Those are all my questions but is there anything else about this history that you think that I'm really missing or any gaps I haven't been aware of?

Neil Schechter:

No, I think I've covered most of them. I may not have remembered certain things, but I certainly have gone on about myself. I'm interested though in how you came to this because that's a remarkably, to my way of thinking, quite a sophisticated—a, your questions are very sophisticated, your understanding is sophisticated, but how you came as an oncology fellow to looking at the history of these kinds of things is intriguing to me.

[End of Audio]
